

Future needs and preferences for hospice care: challenges and opportunities for hospices

A working paper of the Commission
into the Future of Hospice Care

In 2010 the think tank Demos published a report entitled 'Dying for Change' which highlighted some of the challenges facing hospices in the future. Help the Hospices responded to this by setting up the Commission into the Future of Hospice Care to provide guidance, information and options for hospices to inform their strategic position and offerings in the next 10 to 20 years. Opportunities exist across the UK to improve the experience of people who are approaching the end of their life, and that of their families and carers. The Commission is considering how hospices need to develop over the next three to five years to be prepared for the challenges facing them in the future.

Contents

| | |
|--|----|
| Introduction | 03 |
| What the future may look like: challenges and opportunities | 04 |
| The capabilities of hospices to respond | 08 |
| Some suggestions about how hospices should prepare for the future | 10 |
| Priorities for hospices | 14 |
| Next steps and final thoughts | 20 |
| Acknowledgements | 21 |
| Appendix 1: Agenda for the event | 23 |
| Appendix 2: Presentations from the event | 24 |

Introduction

On 24 January 2013, a new report entitled 'Current and future needs for hospice care: an evidence based report'⁽¹⁾ (the CSI report) was launched by the Cicely Saunders Institute (CSI). Written for the Commission into the Future of Hospice Care⁽²⁾ (The Commission) this report anticipates changes in demography and epidemiology in the next decade which will have implications for end of life care, including that provided by hospices. It presents some stark messages about the future – which will present significant challenges as well as opportunities for hospices.

The Commission recognised the importance of this report for providers of hospice care and in partnership with the CSI hosted an event to discuss its implications and consider how hospices might prepare for such a future. The programme offered a wealth of intelligence – derived in no small part from the clarity of its speakers. Dr Barbara Gomes and Natalia Calanzani described the key findings of the report and Dame Barbara Monroe highlighted the consequent challenges and opportunities for hospices. Professor Irene Higginson considered the implications for practice and research, followed by Dr Jo Hockley who described a partnership with care homes as one means of meeting the needs of older people, many of whom have dementia.

Delegates also played an active part and contributed to emerging thoughts about ways forward for hospices in the light of the future they are likely to face. Those present were encouraged to raise questions for further consideration, describe examples of good practice and share thoughts about potential solutions to meet future need. Using iPads, the audience were able to interact with the speakers, vote on key questions and raise pressing issues.

This working document provides a summary of the key points raised during the day. It describes what the future could look like and the way this creates both challenges and opportunities for hospices. It then explores the potential that hospices have to respond; drawing on their established strengths. Finally it makes some suggestions about priorities for action on the part of hospices.

Hospices are strongly recommended to read this working document alongside the CSI report, in order to help their boards and senior management teams understand and prepare for the markedly different landscape that the report highlights. Whilst the report focuses on future needs and preferences for the adult population, the important emerging messages about how hospices need to adapt will also be useful for children's hospices.

(1) Calanzani N, Higginson IJ, Gomes B Current and future needs for hospice care: an evidence based report Cicely Saunders International, Kings College London: 2013
(2) www.helpthehospices.org.uk/commission

What the future may look like: challenges and opportunities

The findings presented in the CSI report present a challenging future for hospices. The number of people dying is likely to rise dramatically, most notably amongst the over 85's who are likely to suffer from chronic conditions and co-morbidities. The demand for end of life care will increase significantly and the nature of the demand for care will be more complex than it is currently. However, amongst these challenges are also significant opportunities that hospices should embrace if they are to succeed and survive in this future landscape. To do so, some honest and sharp thinking is required. One speaker made a clear call that there should be 'no sacred cows' when it comes to the future of hospice care. Furthermore, models of care must be scrutinised and improved upon if they are to continue to meet patients needs and preferences.

Challenges

Increasing numbers of people, including the oldest old

The anticipated changes in the size and shape of the UK population will have a major influence on the future provision of hospice care. According to the Office for National Statistics (ONS), the UK population is expected to increase by 17.5% between 2010 and 2035; by which time over 65's will represent a quarter of the population. The oldest old group of over 85's will reach 3.5 million and will represent almost half of all deaths. The implications of these statistics are significant.

A different set of conditions and related needs

This ageing population will present a different and higher set of care demands with multiple co-morbidities and chronic conditions, including increasing numbers of cases of

cancers and dementia, which arguably will result in a higher demand for hospice care. By 2050, one in three people will die with dementia. The challenge for hospices of responding to the needs of people with dementia, in significantly greater numbers, is not to be underestimated.

“What is the appropriate role of hospices in caring for people with dementia? Is it home based care or work with care homes? Should hospices offer more institutional care for this group of users?”

As people live longer, with chronic conditions, hospices arguably need to be able to manage the provision of care over a longer period. They may need to be prepared for professional engagement with patients and families in a more sporadic fashion and offer increased levels of rehabilitation. Hospices have a crucial role in helping multiple services work effectively together to meet the needs of an individual living with a variety of conditions and in supporting users in transition between services, sectors and specialisms. Currently such transitions are often poorly coordinated, expensive and deeply distressing for patients and their families, giving rise to what one speaker described as a 'chasm of awfulness'.

A changing social context

A changing social context will also pose new challenges; more people will live alone, and families will be more fragmented. With the average family size expected to shrink and more people being in employment there will be fewer people able to provide full time care.

“I wonder whether there is an association with older people who wish to die in a hospice and whether they live alone or not.”

Where family caregivers are still available, it is critically important that they are supported. The length of time that they can sustain this important role is heavily dependent on how much access they have to practical help, advice and care for themselves. How a caregiver experiences the death of a relative or friend can have a great influence on their own health and their expectation for future care. Equally as important is how effectively their bereavement needs are met. The CSI report highlights this as an area in which more innovation is needed.

Limited evidence regarding the value of hospice care

Hospices are confident that they offer high quality care, make a difference and are good value for money on the part of their commissioners and supporters. This is based in part in the feedback that they receive from their users.

Even so, hospices have historically struggled to provide evidence regarding the effectiveness and cost effectiveness of the care they provide. While there is a body of evidence concerning the benefits of symptom control provided by hospices, there is a lack of evidence about their impact on other domains of care and on which models of hospice care work best. Similarly there is little or no research data on the impact of hospice care on caregivers in terms of bereavement outcomes. Although there is a good deal of data on caregiver burden there is little to distinguish the most effective models of support. There was a clear call to 'establish what support is most effective, for whom and at what cost. That is an utterly critical task.'

“How do we engage in more robust research about the effectiveness of hospice care? Could we work collaboratively as hospices on this?”

Limited knowledge about future preferences

As well as being prepared for increased levels of demand, hospices will need to ensure that they are providing the care and services that people most want and need. Hospices must ensure they are sensitive to the shifting needs and preferences of their users including those of people who have previously not used hospice care. As one delegate pointed out 'we need to understand the dynamic nature of people's wishes and the complex trade-offs they might be prepared to make.' Another posed a question about whether the preferences of the baby boomer generation at the age of 70 years will be the same as those of a 70 year old today.

“What might the distinctly different expectations of each baby boom generation be?”

One speaker questioned whether the sector is 'out of kilter' with public opinion, drawing on examples such as the public concern related to the Liverpool Care Pathway at the time of the event. Without doubt hospices need to invest time and resource in understanding more about the priorities of new groups that they may serve in the future – the oldest old and survivors of life threatening and life limiting illnesses are good examples. They also need to explore what patients and families understand about the quality of care they receive and what they consider to be the most important aspect of that care.

Building on place of death to develop other key indicators of success

In order to understand what future patients will want, it is imperative that hospices talk to people more about what dying well means to them. The manner of dying, regardless of where it occurs can be as important for some than dying in a preferred place. At present, emphasis is often put on the place of death but this may need to be widened to also encompass the quality of care received. As an example, hospices should engage with the

oldest old, asking them what care is required to enable them to remain at home and what services they want the hospice to provide.

“Is our approach to preferences static? Failing to understand the dynamic nature of people’s wishes and the complex trade-offs they might be prepared to make as the experience of severe illness unfolds?”

Opportunities

Adopting a leadership role

Hospices have led the way historically in establishing and delivering a model of care which is highly valued by those who use it. They have traditionally enjoyed close relationships with the communities that they serve and as such have responded to local demands for new or increased support for people who are dying and bereaved. They are major employers of professionals who have significant specialist skills and have helped professionals working in other settings to develop similar skills. As such they are ideally placed to be at the forefront of future provision of end of life care, and the development of new models of care and the skills needed to effectively deliver this care.

Meeting additional demands for hospice care

The findings of the PRISMA study⁽³⁾ confirm that older people generally prefer to die in a hospice. There is already a gap between the number of people expressing a preference to die in a hospice and the number of hospice deaths, particularly for the oldest old. This gap is likely to increase in the future and will pose a substantial challenge for hospices that seek to meet new demands for their care. If hospices are to respond and accommodate such choice, they will need to change their models of care delivery. Whilst there may be a case for additional beds, further thought is required regarding what kind of beds would be needed

and whether similar care could be provided at less cost and in other settings.

There is also an opportunity for hospices to continue to increase the support that they provide for people who are at home. The CSI report confirms that home is often the preferred place of care, followed by inpatient hospice care. Enabling people to make genuine choices about the care they receive towards the end of life is one of the core values of hospice care and assisting people to be cared for at home and to die there should be a key aim of hospice care. Data collected nationally between 2007 and 2011 describes an increase in the number of people dying at home – 19.5% to 21.8%. What is less clear is whether hospices played a part in the increase in home deaths and if so, what their relative contribution was. Data to assess this is currently unavailable. This represents a major gap in the evidence of the hospice contribution to home-based end of life care and is something that needs to be addressed as soon as possible.

“In terms of gathering information about those who die somewhere other than in a hospice but who are in receipt of hospice care, we are beginning to share the NHS numbers of our patients with the CCG’s to help them track hospice involvement.”

Knowing more about what people want

Current evidence shows that often people’s preferences at the end of life are never articulated, poorly communicated between professionals or ignored. An opportunity exists to increase the use of advanced care plans to enable people to express their wishes about their preferred care in the future. If more advanced care plans were in place, hospices would be better placed to help people plan their care in a variety of settings, including care homes, with hospice support as necessary, if this was required.

(3) Gomes B, Higginson IJ, Calzani N et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, the Netherlands, Portugal and Spain. *Ann Oncol*. 2012; 23: 2006–15

Coordinating health and social care

Speakers emphasised the opportunity for hospices to take a lead in coordinating health and social care for people living with chronic and multiple conditions in the future. This care will need to be well integrated, and will be multi-layered, drawing in many different providers and elements of support. Hospices can help users and other professionals to make decisions about the shape of the optimum care package as well as modelling an approach for personalised care encompassing health and social needs. Hospices can also contribute to such packages of care, offering rehabilitation and support in survivorship as well as end of life care.

Adopting new and flexible approaches to hospice care

The hospice sector will need to be more flexible in meeting patients needs and preferences by adopting a variety of new models of care. These could include more inpatient beds, hospice supported beds in other settings and halfway house models that enable elements of hospice care to be delivered to people who are being cared for by their families or other carers. Models of inpatient and home-based care need further development. Much of the infrastructure is in place, but hospices need to take the next step towards fulfilling this role – establishing a menu of options for users with multiple and variable needs. An important next step is to ensure that hospices communicate a clear message about hospice supported care and other services they provide beyond inpatient care.

Diversification will also be required in terms of models of care to better meet the needs and preferences of emerging groups of users or those

that have traditionally felt excluded from hospice care. This will in part be assisted by working with new partners to establish new effective and acceptable models of care, whether in hospice, in hospital, at home or a care home. Only by testing and proper evaluation will hospices be able to establish the best models of care and the most valuable partnerships in which to engage.

Collecting data to support the value of hospice care

Just repeating the mantra of being “a good thing” will not be enough to convince local commissioners and others of the value of hospice care in the future. The sector needs to become better at demonstrating the contribution that hospices make to the health and social care economies at local and national levels. Local strategic planning based on local population data, as well as registering and monitoring data on hospice usage and provision will provide essential baselines from which this evidence can be built. There is excellent local data available for all local authority areas from the UK End of Life Care Intelligence Network (www.endoflifecare-intelligence.org.uk) and the recent end of life care atlas developed by Marie Curie Cancer Care (<https://www.mariecurie.org.uk/atlas>).

Hospices will need to provide evidence of their reach and effectiveness to fight their corner with commissioning groups. Providing outcomes data reflective of meaningful standards will put hospices in a strong position and help confirm to local commissioners how they represent value for money. It was suggested that hospice providers in the UK learn from Australian palliative care providers who have developed good data on outcomes.

The capabilities of hospices to respond

Hospices must address future challenges as a matter of priority as well as embracing the opportunities that are unfolding around them. Those speaking and attending the event were clear that hospices are well placed to do so if they build on existing strengths. These strengths are significant but must be protected and developed to ensure a future for the hospice.

Being at the heart of the community

Hospices that are integrated into their local communities are ideally placed to capitalise on some of the opportunities described earlier. They are well positioned to establish themselves as community hubs, to develop new and expanded outpatient and home based services, augmenting inpatient hospice services where these are available. Such services are likely to be more efficient in their use of resources and there is evidence that they are well received by users. Some participants commented that they had found patients to be more willing to travel to meet with professionals at the hospice than they had previously imagined.

In being integrated, hospices can locate their staff where they are best placed to deliver care that is easily accessible and appropriate. For example, satellite services and the co-location of hospice nurses in community nursing teams, have both increased access to care and improved the efficiency of service delivery.

Using volunteers

Volunteers offer huge potential for hospices, but to make the most of them, hospices will need to develop this workforce and increase the scope of their work. For some roles, an opportunity exists to increase responsibilities, to provide accredited training and to offer apprenticeships as a pathway to employment. To compete with national charities, hospices may need to provide NVQs or similar in

order to continue to attract large numbers of high quality volunteers offering a range of skills. In so doing, they could engage with volunteers who offer a different set of demographics and with new skills, such as technological capability.

Hospices need to think more creatively about how they use their volunteers; there are a multitude of tasks they could perform. They could provide at least part of the solution for ensuring continuity of care for long term patients. One delegate cited a project that was used to improve nutrition for people with dementia by using volunteers for social dining experiences. The Commission has developed a separate stream of work to consider the future roles of hospice volunteers⁽⁴⁾.

Working closely with other providers

Many hospices already work closely with other providers in the statutory and voluntary sectors. Such partnerships will be key to getting care right in the future. Serious thought needs to be given to how best to work with organisations such as the Alzheimer's Society with whom hospices have had much less engagement historically but who could be key to developing new models and approaches to meet the needs of new groups of users or new sets of needs.

Building on existing expertise

Hospices are repositories of professional knowledge and expertise as well as confidence and competence. This places them in a powerful position to tackle forthcoming challenges. Internal and external training will be important drivers for improved care. Delegates heard of existing research which confirms that a third of all GPs in this country have never had a conversation to establish an advanced care plan; this major gap in provision may well be addressed by delivering more education to key professionals working in primary care.

(4) The Commission into the Future of Hospice Care (2012) Volunteers: Vital to the future of hospice care. London: Help the Hospices.

Retaining an innovative approach to developing new services

As small organisations, hospices are inherently flexible and should capitalise on their ability to experiment with new ideas and to turn ideas into action quickly – while being careful to ensure they learn from their mistakes. Hospices need to work more closely together, so that they can better share their learning. This way, they can retain an edge as pioneers in end of life care and prepare quickly to respond to new needs and preferences.

Some suggestions about how hospices should prepare for the future

Use a population based approach to planning services

Hospices need to engage in a strategic approach to planning their future services. This should take into consideration the current and anticipated future shape of the populations they serve. They should bear in mind the growing user groups, particularly the oldest old, and consider what models of care they might use to meet the anticipated increase in demand for hospice care and whether this necessarily means that more inpatient beds are part of the solution.

Collect more data and provide more evidence regarding the value of hospice care

Hospices cannot rely on their past reputation as providers of excellent care to secure their future. They must provide rigorous data as evidence of their reach and impact. Specifically, they must collect and present data related to the effectiveness and cost effectiveness of their services.

Hospices will need to show which models of care are most effective, for whom and at what cost. To do so, they must develop their capacity to record and collect both qualitative and quantitative data on the care they give in all settings. This will be vital if they are to retain a lead role in the delivery of local end of life care. Working collaboratively, hospices may be able to develop partnerships with academic institutions and develop the capacity to collect and interpret outcome data. Volunteers may also play a significant role in the collection of data.

Deliver care to more people

The majority of hospices are arguably not providing sufficient care to ensure they serve as the most significant provider of end of life care in their local area. This is for many different reasons, mainly historical. In the future, hospices must

consider the risks that come with such a specialist and niche role in a market which is becoming increasingly crowded.

Engage further with local communities

Community engagement is a key mechanism for ensuring that hospices focus on the needs and preferences of local people, rather than simply seeking to deliver outputs required by commissioners and other players. It was suggested that some work was needed to establish what willingness exists within the community for collaboration in service planning and, where possible, to draw on these views to establish new service models for the future. There was also a call for more cohesion and sharing of best practice within the sector when it comes to community engagement – for example learning from each other about how best to bring the community into the hospice building as well as taking the hospice out to the community.

“Natalia mentioned the role of hospices in engaging the communities: does this mean they should lead a discussion with the public about how we want end of life care to be in the future?”

Establish a workforce and culture that is fit for the future

To meet a new range of challenges and demands, hospices will need a flexible and well trained workforce that is able and willing to adapt to the future. Hospices will need to review staffing levels and skills to create a workforce that is ready to respond to new needs and new preferences for care from future users. The process of considering future patient needs, and identifying skills required in staff and volunteers will also help challenge thinking around the involvement of volunteers in care giving.

Use volunteers differently

A motivated, multi-skilled and valued team of volunteers will be a key part of the future workforce – helping to care for more people in different ways, maintaining links between the hospice and its communities and providing a competitive advantage for hospices when they are in competition with other end of life care providers. Drawing on the responses from delegates, it was clear that a national training programme would be considered a helpful development.

There was also a clear call for more sharing of best practice related to volunteering. As one delegate said ‘we need to have, in one place, and easily accessible, a repository of good practice related to volunteer utilisation within the sector. This means that, before we reinvent the wheel we should learn from the experiences of colleagues.’ This sharing of learning would help to spread ideas for using volunteers in different roles. This was felt to be a key development for the future. Ideas for innovation in this area included up-skilling volunteers in research and data collection and using their skills in social media.

“Volunteers are vital – I agree. There is much to learn from elsewhere.”

“Dying Matters can be used as a vehicle to reach, inspire & help train volunteers.”

Build partnerships in care

Hospices will not be able to meet the expected increase in demand on their own. Greater collaboration and new relationships are required in the future, with both existing partners and new ones. As one delegate pointed out, it is about making the service ‘bigger, leaner and more efficient.’

A variety of partnerships were discussed including the best ways of working with care homes, proactive engagement with academic centres and strong networks of support with other hospices through which learning could be shared. Working together will help hospices develop the strategic political leadership required for the future landscape. One of the speakers spoke convincingly of the shared opportunities for hospices and academic centres to work closely together in a sustained way.

Tell a stronger story about the scope of hospice care

Hospice care is widely seen as inpatient care, which is not reflective of its true breadth. Hospices are increasingly establishing themselves as strong community based hubs with increased outpatient, drop in and day care facilities. Making sure that the public, commissioners and other funders are aware of the scope of care is key to helping hospices position themselves in the future. Such a story is best supported by strong evidence and could be something that hospices work on together to establish as consistent and effective a voice as possible.

Develop stronger business acumen

Hospices need to get business-like and learn internationally from other sectors. They need to find the right models for funding and service delivery, and take some action to be ready for the new world. New alliances and relationships are essential to meet unprecedented demand.

There will be a variety of options about how hospices take advantage of opportunities and hedge against threats. Hospices need to consider carefully how they respond. What response is required will need to be determined locally but principles and their application can be shared nationally.

Work differently with care givers

Hospices should do more to value and support carers as partners and beneficiaries of support. Support and help for carers should be more extensive, providing them with the aid they need to do their job better whilst retaining their relationships with those they are caring for. Put quite simply; 'by understanding the carers needs, we can assess what support, if any, they need. This would improve the level of service they offer as they're being given the support and time that they need themselves.' There is significant work to be done in this area.

Deliver and coordinate integrated hospice and social care

Hospices can and should take the lead as the coordinators of 24 hour hospice and social care, working with other specialists to provide ongoing, joined up, long term care for the benefit of patients, families and carers. However, the challenge here is to establish a model that can be adopted with different levels of funding and varying philosophies of care management.

Work differently with care homes

Many delegates were keen to explore the potential opportunity for hospices to work more closely with care homes. A greater understanding of the individual capacity of local care homes to give good care at the end of life, would be a first step in enabling a local hospice to identify what role they might be able to adopt alongside each home.

Hospices should seek to establish new working relationships with care homes, viewing them as equal partners, providing them with training and education and collaborating with them to enable the delivery of hospice care in the care home

setting. This would enable hospice care to reach more people, particularly the oldest old and those with dementia, whilst ensuring the quality of care received. Further work is required on the right business models for such partnerships.

“The question is: how do hospices work in partnership with care homes while differentiating themselves as something different.”

“Should the work of hospices with care homes be free or at financial cost? If the latter, how do we persuade care homes to pay?”

Use technology to support patients, carers and other professionals

Hospices need to consider ways of using technology to provide individualised support and care for patients where they want it, as well as collecting patient related data on the care that they receive. This is an area ripe for innovation and exploration. There was a clear recognition that advances in technology can be used to help overcome cultural, geographical and other barriers of access. Technology can also be used to help and support carers more effectively. New technology provides the opportunity for hospices to be more connected to each other, and the NHS. All these ideas are open for any hospice to explore.

“We need to explore telemedicine for palliative care.”

“We need to be completely connected to the NHS.”

“We need downloadable resources – considering language and cultural needs.”

Build new models of community based hospice care

Hospices need to invest significantly in building and delivering models of community based care that are fit for the future. There is a strong acceptance of the shift from institutional care to care at home for many people who face progressive and life threatening conditions but there is less clarity about what models should be developed and expanded. Such models need to take into account the current expressed preferences of many individuals to die in a hospice and to understand more about what motivates this choice and to consider how these valued aspects of care might be provided across a range of possible settings.

“Is there not more mileage in changing people’s perception of the hospice as a place to die by encouraging more parallel care with other specialities so that we are not seen as a place to go when they can do no more?”

Priorities for hospices

The Commission drew on the expertise of delegates for their thoughts on identifying and prioritising how hospices should respond to the scale and scope of future end of life care needs outlined in the CSI report.

Participants worked in pairs to identify up to five key responses needed from the hospice movement - altogether they gave us 128 different ideas.

These ideas were grouped into the following 10 clusters:

1. working differently with care homes;
2. working better to support carers;
3. engaging more with the community;
4. delivering and coordinating integrated hospice and social care;
5. working differently to collect data, measure outcomes and generate evidence;
6. building new and defined models of community hospice care at scale and cost;
7. building new partnerships in care;
8. using technology to support patients, carers and other professionals;
9. using volunteers differently; and
10. developing a mobile, flexible workforce.

For each idea, participants identified short descriptions of the work that needed to be undertaken or the reason for the importance of adopting a new way of thinking.

We offer this feedback collected during the day in order to give a rich sense of the shared thinking. All the grouped comments given below are from participants – they have been tidied up to correct typing and ensure that the sense is clear but we have deliberately left them in the note form in which they were offered.

Working differently with care homes

- Working with care homes in a different way, expanding on just teaching, listening more - developing new models of care/shared funding and working on conflicting principals re funding.
- Acceptance that hospice care can be delivered within a care home context.
- Work with nurse educators to transfer specialist palliative care knowledge to care home providers to empower them to provide better care.
- Hospices training and supporting staff for dementia in care homes.
- Collaborative working with nursing homes to educate and empower staff to care for their residents.
- Empowerment of staff in care homes.

Working better to support carers

- Promoting self-care and self-management for patients and for care givers and carers. Get to know our community. Therefore not to presume we know what our community wants and needs.
- More work with care givers (paid and unpaid) especially social care.
- Broaden out into personal social care as well as health care for both the patient and the family.
- Extended programme of outpatients support services for both patients and families / carers.
- Achieving realisation that carers are also hospice patients in their own right...irrespective of whether or not the 'patient' wants our services.
- Improved ways of supporting family carers at home, eg with immediate access to advice from a known professional.

- Stop paying lip service and accept carers as partners rather than beneficiaries.
- Proactive carer awareness and support, signposting, empowerment – a range of ways to support care givers.

Engaging more with the community

- Hospices have to re-engage with the concept of death as a social process, of which clinical is a part, rather than a clinical process of which social is a part.
- Making the hospice building more community focused to enable more listening and engagement in communities. Increase in self help groups and volunteer led activities, including bereavement support.
- Using expensive facilities in innovative ways to engage community support and break down barriers.
- Supporting existing informal networks in communities and working out where the hospice fits in, not disempowering people and communities.
- Community hubs – bringing the community into the hospice to demystify what hospices can provide to the local population.

Delivering and coordinating integrated hospice and social care

- More collaborative approach with other providers for better coordination of care.
- Integration of all available services for patients facing long term life limiting illnesses – hospice care working in partnership with other specialists and not just being brought in when there is ‘nothing more that can be done’.

- Coordination of all care services, for the benefit of patients, families and carers at the end of life – how to achieve it, and integration of services without losing the ethos of specialist palliative care and hospice care.
- Whole hearted engagement with wider care system. End preciousness.
- Whole system coordination. Hospice leadership of development.
- Hospices should be central to co-ordination of care. There would be partnership opportunities where we wouldn’t actually be hands on but would work closely with other organisations.
- Coordination and responsiveness to need 24 hours a day.
- Broader use of triage based on patient assessment leading to consistency and coordination as well as meeting what is important to patient and carers.
- Collaborate with local social services to improve provision of social care at the end of life.
- Coordination – what does this mean and what is our remit – we need to define this. Hospices doing it to a degree informally, need support to formalise and learn from those who have achieved this.
- Commissioned models that support integrated working between organisations.
- Commissioned coordination of the whole end of life pathway

Working differently to collect data, measure outcomes and generate evidence

- Hospices and academic joint posts.
- Develop a clearly defined standard for hospice at home services to be able to measure outcomes between services.
- Education - Hospices have done lots on education can this be a model for how to generate evidence more.
- What is the most effective model of home care.
- Develop health intelligence through informatics, to identify the data set for outcome measures to inform research practice and service development (need to work to agreed definitions).
- Demonstrating value through outcomes: greater evidence and research and integration with research communities: common outcome measures and common descriptors of services.
- Develop capacity to record and collate data and build evidence of outcomes impact, effectiveness, etc.
- Joint outcome measures, clear guidance to future commissioner on what denotes high quality end of life care, supporting the concept of hospice, including opportunity to benchmark.
- Valuing other providers, being prepared to adapt and not seeing hospice as an elite, recognising different routes to improve end of life care, but maintaining the essence of specialist palliative care medicine/ nursing and the contribution that knowledge and experience can make to the patient and carer experience.
- Identify what it is that makes hospice care “good” through qualitative as well as quantitative research.

Building new and defined models of community hospice care at scale and cost

- A new model of hospice care that embraces the needs of people with dementia.
- How do we develop models of care for older people with limited family support living alone (without dementia)?
- Opportunities for families containing a dying person to move into a flat with easy access to professional help.
- Developing a model of integrated hospice and social care to meet changing care needs and provision, not just at the end of life.
- Reshaping use of day centres.
- Using rehabilitation outcome models.
- Reconfiguring responsiveness of community service, eg hospice at home and community palliative care teams.
- New models of care for non cancer. NB: there're distinct groups with different needs and there is a tendency to group them together.
- Forums that enable sharing of non cancer models of working at the end of life.
- Being prepared for people who have multi-morbidities at home and in care homes.
- Extend influence and reach through sustainable partnerships, eg care homes and working with other charities, eg Alzheimer's Society.

Building new partnerships in care

- Sharing end of life care preferences electronically (Electronic Palliative Care Co-ordination Systems) and getting GP's competent and confident in having advanced planning conversations. How we can expand on Electronic Palliative Care Co-ordination Systems to be an enhanced data set for bench marking?
- Identify and develop new partnership models to signpost and refer people appropriately and establish joint working.
- National database and benchmarking programme.
- Improving partnership working.
- Working much more in partnership and collaboration with others: locally and nationally.
- Developing better working relationships with other professionals involved in long term conditions to work in partnership/collaboration.
- Breaking down the barriers to partnership and collaboration, and understanding implications – legal, etc.
- Better collaboration/engagement with GP practices.
- Willingness to share space with other organisations (fundraisers nightmare).
- Using rehab teams who work in hospices to help patients with long term conditions to maintain function and independence, eg lymphedema clients.

Using technology to support patients, carers and other professionals

- Could we make more use of technologies?
- Use of technology to collect patient related outcomes.
- Increased use of technology to maintain contact between patients, families, carers and professionals.
- Getting technology which works for patients, (eg tele-health) and enabling staff and volunteers to give good individualised support.
- Virtual hospice: develop flexibility to respond to needs wherever they might be and not being constrained by a building and equip ourselves to respond to the full picture and not what is known to us. Have the courage to step away from what is familiar.

Using volunteers differently

- Gear up for increased need - using voluntary workforce to enable the scaling up at reduced cost.
- Using volunteers in more care giving roles or indirect care, eg audit and research.
- Develop the potential of volunteers in all places of care.
- Building capacity through the use of volunteers.
- Grow the expertise of the volunteers so that we are not putting boundaries in the way of volunteers. Volunteers want to be hands on.
- Developing use of volunteer skills in all elements of organization, ie education.
- Explore models of effective low cost volunteers.

- More imaginative use of volunteers.
- Use of skilled volunteers to support the work we do, eg welfare rights advice, befriending including practical support, eg shopping, feeding, etc.

Developing a mobile, flexible workforce

- Integrated community care teams working across population defined areas with specific skill mix and staffing levels.
- Developing a 'mobile' multiagency workforce working between and across services responding to patient care needs at various levels of care provision and advice preventing crisis and carer exhaustion.
- Flexibility and creativity with models of staffing.
- Development of workforce-broader vision, flexible, challenging assumptions, hospice cultural change.

Many participants took the opportunity to reflect on future challenges and approaches to present what they thought were the dilemmas that characterised that future. These are presented below and some pick up on other themes that were evident during the day such as the need to adapt to the specific needs of the frail elderly, to ensure 'fairness' in the way in which access to hospice care is assured, the need to adapt to the growing 'market' for care particularly in England and the undoubted requirement to adapt to the highly constrained financial environment that will dominate the foreseeable future.

Dilemmas and challenges

- Change attitudes within hospices: be more open, we don't always know best; we can learn from others. There is a danger that hospices are perceived as exclusive and elitist.
- Work with care homes in a different way, expanding on teaching, listening more and working to address the issue of patients paying £1000 per week for care but hospice offering charitable help to deliver good end of life care.
- Commissioners need to take a more holistic view regarding funding for services across the community providers. Managing patient expectations which are being heightened by promises of choice will require us to have more resources.
- Consider services for the frail elderly, highlight the impact of good nutrition and slowing down frailty.
- Greater involvement with frail older people including those with dementia (with care homes, in their own homes and in the hospice itself).
- Careful approach across all care settings so as not to dilute or stretch limited resources to breaking point.
- The role of hospices in providing long-term care.
- How would the model look like for rehabilitation and survivorship care?
- Hospices may need to develop a hospice care agency to support patients and prevent carer burnout.
- Hands on hospice supported care, closer to where people want to be with a variety of services and settings.

- Identify the ‘sacred cows’ and lose them!
- Addressing the terminology we use to describe our services – being honest and open without unduly frightening patients and carers.
- Be creative in our approach to delivering quality palliative care at different levels and not necessarily becoming too medicalised.
- Using the building in a more imaginative way – sweating the asset!

Another topic that exercised participants and provoked them to ask questions concerned the need for hospices to do more to ensure access to services and to consider the need for equity in that access.

Access to hospice care

- Defining a system to enable/allow patients and families to access available care without bureaucracy – develop information sharing portals.
- Who should access inpatient beds? With constraints on the numbers of inpatient beds, who should access them?
- In order to remain accessible for acute specialist symptom management or complex end of life care there is a need to have a hospice nursing home to accommodate the needs of the frail elderly. Should this be part of the hospice remit or does the hospice support existing nursing homes to do this?
- We must grasp the implications of 24/7 services in terms of availability of services and do something about it.

- We must change people’s perceptions of palliative care to make sure it’s available from whenever it is first required and ensure a greater congruence between children’s and adult palliative care.
- We need to be able to offer access for an acute admission to support patients receiving hospice care in the community – the hospice needs to be able to respond urgently with staff or immediate bed availability.

Thinking about access across the population

- Dilute the holistic approach traditionally associated with hospice care. Think about quantity of care not just quality of care.
- Develop a standard clinical staff model for hospices nationwide based on an agreed defined formula.
- Develop common standards for care not defined by organisations, same expectations across care settings: home, hospice, care homes, hospital, etc.
- Thinking about populations not diseases – define the wider social, clinical and economic benefits of hospice care.

Next steps and final thoughts

There is no doubt that the CSI report and its launch event offers a significant opportunity for hospices to prepare for the future. Most importantly the Commission hopes that the CSI report and this account of the discussion that surrounded its publication will help hospices envisage what the future may look like. This is the first step towards hospices preparing effectively for that future.

In terms of next steps, the Commission is looking now to consider further the key areas that delegates identified as requiring further exploration. How these are addressed will take various forms.

Of note, work is planned on:

- the future of research within the hospice sector;
- a review of the research concerning the effective models of support for carers;
- a forthcoming event and toolkit addressing the question of how hospices can effectively work in partnership with others; and
- a short paper considering the evidence based models of supporting young people in transition from children's to adult services.

The Commission, in conclusion, is most grateful to the Cicely Saunders Institute for its significant contribution to its work and all who attended the day for providing such rich and creative dialogue.

Acknowledgements

The Commission is grateful to the following for their contribution to this report: to Tom Tanner, Laura Hamblin, Heather Richardson and Steve Dewar for their authorship of this report; to Professor Irene Higginson and her team at the Cicely Saunders Institute for hosting this event and to Dr Teresa Tate for chairing it. It would also like to thank those who attended as delegates for their energy, ideas and engagement in the process of thinking about the future and how best to be ready for it. Below is a list of all the people who attended the event.

Chair:

Dr Teresa Tate

Speakers:

Dr Barbara Gomes

Natalia Calanzani

Dame Barbara Monroe

Professor Irene Higginson

Dr Jo Hockley

Heather Richardson

Steve Dewar

Delegates:

Heather Aldridge – Sue Ryder Care

Helen Bennett – Alexander Devine Children's Hospice

Brian Bolt – St Elizabeth's Hospice

Jo Boyd – Les Bourgs Hospice

Liz Brown – Dorothy House Hospice

Alison Bunce – Ardgowan Hospice

Colin Burgess – St Peter & St James Hospice

Ruth Burnhill – Weld Hospice

Andy Burt – St Barnabus House Hospice

Claire Butler – Pilgrims Hospice

Jane Bywater – St Michael's Hospice

Zena Cairns – St Catherine's Hospice

Louise Cameron – St Clare Hospice

Simon Caraffi – St Peter's Hospice

Simon Chapman – NCPC

Laura Cottingham – St Rachael's Hospice

Pam Court – Saint Francis Hospice

Carl Davies – Thames Hospicecare

Daniel Faragh – Marie Curie Cancer Care

Janet Ferguson – Eden Valley Hospice

Margaret Gallety – St Peter & St James Hospice

Tracey Livingston – Nightingale House Hospice

Stephanie Griffiths – Wisdom Hospice

Laura Hamblin – Help the Hospices

Jean Hindmarch – Help the Hospices

Debbie Ho – Prospect Hospice

Richard Horner – Barnsley Hospice

David Houston – Trinity Hospice

Steve Hoy – Demelza Hospice Care

Martin Jervis – Thames Hospicecare

Emma Johnson – St Leonards Hospice

Penny Jones – Greenwich & Bexley Community Hospice

Shaheen Kahn – Cicely Saunders Institute

Michael Kerin – St Joseph's Hospice

Gail Linehan – St Raphael's Hospice

Rachel McCarty – North Devon Hospice

Paula McCormack – Highland Hospice

Cath Miller – St Gemma's Hospice

Anne Mills – Ardgowan Hospice

Lynn Morgan – St Elizabeth's Hospice

Tilde Nielsson – Marie Curie Cancer Care

Sharon Nuttal – Farleigh Hospice

Shaun O’Leary – St Catherine’s Hospice
Jane Petit – St Elizabeth’s Hospice
Catherine Piggin – Prospect Hospice
Lara Pivodic – Kings College London
Sarah Riches – St Giles Hospice
Libby Sallnow – St Joseph’s Hospice
John Savage – Nightingale House Hospice
Arnold Simanowitz – St Wilfred’s Hospice
Heather Skinner – National Gardens Scheme
Sarah Smith – Trinity Hospice
Carol Stone – EllenorLions Hospice
Tom Tanner – Reporter
Sheila Tonge – Bolton Hospice
Jackie Tritton – Peace Hospice
Maxine Trotter – Help the Hospices
Colin Twomey – St Wilfrid’s Hospice
Nicky West – St Michael’s Hospice
Alison Wetherall – St Michael’s Hospice
Sarah Whitfield – Commission member
Paula Wilkins – Hospice in the Weald
Fiona Wordley – Willen Hospice
Neil Wight – Willowbrook Hospice

Help the Hospices is very grateful to The National Gardens Scheme for supporting the Commission and its publications.

The National Gardens Scheme has been supporting Help the Hospices since 1997 by opening gardens of quality, character and interest to the public, helping to raise over £2.6 million for hospice care. They publish the ‘Yellow Book’, an annual best seller listing gardens that open for the scheme.

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Appendix 1: Agenda for the event

24th January 2013: Lecture Theatre, Cicely Saunders Institute

Chair: Dr Teresa Tate

10:30 Welcome and Registration

10:45- 11:00 Welcome and introduction to the event and the Commission

Dr Teresa Tate, Medical Advisor,
Marie Curie Cancer Care

11:00- 11:30 Introduction to the publication and its key findings

Dr. Barbara Gomes and Natalia Calanzani

11:30- 12:00 A hospice response: Questions raised; opportunities identified

Dame Barbara Monroe, Chief Executive,
St Christopher's Hospice

12:00- 12:30 Questions and discussions

12:30 Lunch

13:30- 14:00 Looking forward: Implications for practice and research

Prof. Irene J Higginson, Professor of
Palliative Care, Policy and Rehabilitation,
King's College London / King's Healthcare
Partners Scientific Director,
Cicely Saunders International

14:00- 14:30 Thinking differently – new approaches for frail older people in care homes

Dr Jo Hockley, Nurse Consultant (Care
Homes), St Christopher's Hospice

14:30- 15:00 Identifying future priorities for change (Part 1)

15:00 Tea and Coffee Break

15:15- 16:00 Identifying future priorities for change (Part 2)


Heather Richardson, National Clinical
Lead, Help the Hospices and Steve Dewar,
Consultant to the Commission



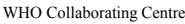

Appendix 2:

Presentations from the event

1. Key findings from 'Current and future needs for hospice care.'

Natalia Calanzani, Dr Barbara Gomes





Current and future needs for Hospice Care: An evidence-based report

Introduction and key findings

Natalia Calanzani and Barbara Gomes
King's College London, Cicely Saunders Institute
Department of Palliative Care, Policy and Rehabilitation

Section 1. Introduction (p. 7)



- **Independent hospices: crucial in hospice care provision**
 - Inpatient beds, day care, home care, community engagement...
- **Many challenges now and ahead influencing hospice care provision**
 - Health/social care funding, new Acts and Bills
 - Unequal access to hospice care by region, ethnic group...
 - Changes in mortality trends in the UK population (Section 3)
 - Meeting people's preferences and priorities for care (Section 4)
 - Making sure hospice care is beneficial to patients and their families, while also being cost-effective (Section 5)

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Section 2. Methodological notes (p. 8)

- Definition of hospice care

“Hospice care seeks to improve the lives of people living with a progressive and life-threatening condition. By offering high-quality, specialist palliative care it helps them to live as actively as they can to the end of their lives, however long that may be. It not only takes care of people’s physical needs, but looks after their emotional, spiritual and social needs as well. Hospice care also supports carers, family members and close friends, both during a person’s illness and during bereavement”

(Help the Hospices Hospice and Palliative Care Directory 2012)

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Section 2. Methodological notes (continued)

- Focus on the adult population
- Analysis of official mortality data from 2007 to 2011
 - Place of death categories not consistent across the UK countries
- Latest available UK population projections
- Literature search for population preferences for place of care/place of death in the UK
 - Factors associated with inpatient hospice preferences - PRISMA
- Focus on systematic reviews and RCTs to report effectiveness and cost-effectiveness



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Section 3. People are living longer, but often with a life-limiting condition (p. 11)

- Less deaths from infectious diseases, more children surviving into adulthood and improved life expectancy
- Childhood mortality replaced by deaths at an older age
 - Older age closely linked with cancer and dementia; frailty and comorbidities
 - Different illnesses can have different trajectories – but symptom control a common requirement
- Plus: smaller families, people living alone, increasing number of births after the 2nd WW

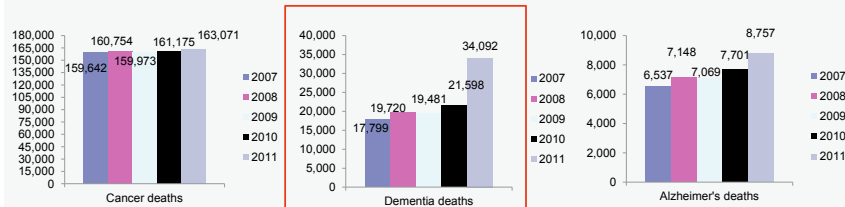


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2007-2011: reduced overall number of deaths, increased cancer/dementia deaths (p. 12)

- **Reduction in overall number of deaths (all the UK countries)**
 - UK deaths reduced from 573,504 in 2007 to 551,153 in 2011
 - At least 79% of deaths in each country amongst those aged 65+
- **Cause of death with similar distribution across the UK**
 - Slight increase in the number and proportion of cancer deaths
 - Increase in the number and proportion of dementia deaths



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England and Wales: Reversal of trends in place of death with more people dying at home (p.14)

- Increase from 19.5% in 2007 to 21.8% in 2011
- But older people, women and non-cancer patients still die at home less often

| | 2007 n (%) | 2008 n (%) | 2009 n (%) | 2010 n (%) | 2011 n (%) |
|-----------------------|---------------|----------------|---------------|----------------|----------------|
| Age | | | | | |
| All ages | 98,271 (19.5) | 101,090 (19.8) | 99,562 (20.3) | 102,416 (20.8) | 105,354 (21.8) |
| Up to 4 years | 256 (0.5) | 232 (0.4) | 215 (0.2) | 201 (0.5) | 206 (0.5) |
| 5-14 | 180 (0.2) | 163 (0.2) | 144 (0.2) | 129 (0.2) | 133 (0.2) |
| 15-44 | 4,991 (28.7) | 5,290 (30.0) | 5,313 (31.0) | 5,065 (31.3) | 4,976 (22.4) |
| 45-64 | 20,020 (20.5) | 20,540 (31.2) | 20,173 (31.4) | 20,455 (31.9) | 20,603 (32.9) |
| 65-74 | 20,994 (25.7) | 21,806 (26.4) | 21,488 (27.0) | 21,467 (27.1) | 22,609 (28.8) |
| 75-84 | 30,836 (19.3) | 30,915 (19.6) | 29,023 (20.0) | 30,893 (20.9) | 31,318 (21.8) |
| 85 and over | 10,954 (12.0) | 22,344 (12.3) | 22,334 (12.2) | 23,705 (13.1) | 25,452 (14.1) |
| Gender | | | | | |
| Male | 14,873 (22.8) | 16,534 (23.3) | 16,148 (23.6) | 17,604 (24.2) | 18,962 (25.1) |
| Female | 43,400 (16.5) | 44,556 (15.7) | 43,414 (17.2) | 44,762 (17.3) | 46,412 (18.5) |
| Cause of death | | | | | |
| Cancer | 34,869 (24.7) | 36,183 (25.8) | 37,345 (26.8) | 38,558 (27.3) | 41,040 (28.7) |
| Non-cancer | 63,402 (17.5) | 64,707 (17.8) | 62,217 (17.2) | 63,858 (18.2) | 64,314 (18.9) |

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England and Wales: marginal increase of inpatient hospice deaths (p.15)

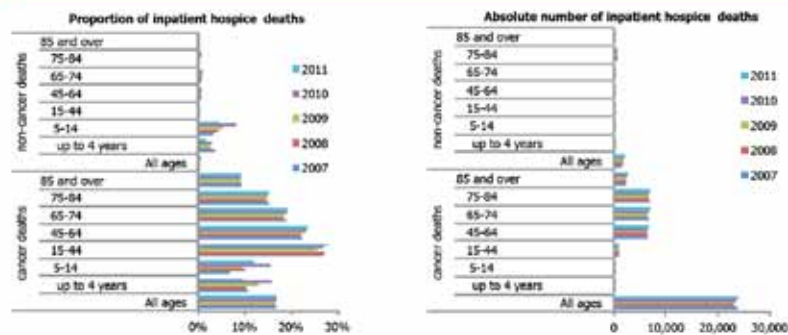
- Increase from 5.0% of all deaths in 2007 to 5.4% in 2011 (1,008 additional deaths)
- Cancer patients died more often in inpatient hospices
 - 16.9% of cancer deaths (n=24,185) compared with less than 1% of non-cancer deaths (n=2,176) in 2011
- Oldest old and women also die in hospices less often – similar to home death trends

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England and Wales: marginal increase of inpatient hospice deaths (p.15)

Figure 1 – Proportion and absolute number of inpatient hospice deaths by age and cause of death in England and Wales (2007–2011)



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England and Wales: 5-year trends harder to interpret for hospitals and care homes (p.16)

- **Decrease of number and proportion of institutionalised deaths up to 2009** (Gomes et al *Palliat Med* 2012)
 - But at least 50% of deaths were in hospital/care homes in 2009
- **Number of hospital deaths decreased 6% (2010-2011)**
- **Number of care home deaths increased 3% (2010-2011)**
 - 24.8% of all women's deaths while 13.0% of men's (2011)
 - More than 1/3 of 85+ deaths happened in a care home (2011)



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What about place of death in Scotland and Northern Ireland? (p. 17)

- **Cancer deaths in Scotland (2007 and 2008)**
 - At least half of cancer patients die in hospital
 - 24.7% of cancer patients died at home in 2008, while 18.7% died in inpatient hospices
 - Those aged 85+ die less often at home and in inpatient hospices
- **In Northern Ireland, at least 50% of patients die in hospital**
 - Proportion and number of deaths decreased for hospitals and increased for nursing homes from 2007 to 2011



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Trends in hospice care services: work in progress (p.18)

- **Challenges: register patient data across providers; patients can receive care from more than one provider**
- **Official mortality data offers limited help; other available statistics have limitations**
 - Palliative Care Directory: number of providers and range of services, but no information on patient activity by provider
 - Minimum Data Set: information on patient activity, but heavily dependent on responses from providers; plus patient activity based on number of contacts

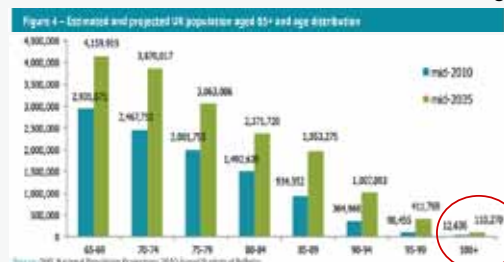


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Challenges ahead: increasing number of older people, changes in family structures (p. 18)

- **UK population expected to increase 17.5% from 2010 to 2035 (from 62.3 mi to 73.2 mi)**
- **Baby-boom generations reaching older age**
 - Aged 65+ to account for almost 1/4 (23%) of the UK population, number of centenarians will increase more than eightfold



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Challenges ahead: escalating number of deaths replaces decrease in mortality (p. 20)

- **Number of deaths projected to increase very soon (from 2015)**
- **Aged 85+ projected to represent 49.5% of deaths in the UK in 2035 – a total of 328,469 deaths for this age group**

Table 6 – Actual and projected number and proportion of oldest old deaths in the UK (2010-2035)

| 85+ deaths | 2010 | 2015 | 2020 | 2025 | 2030 | 2035 |
|------------|----------------|---------------|---------------|---------------|----------------|----------------|
| 85-89 | 104,357 (16.6) | 95,974 (17.3) | 94,532 (16.8) | 97,990 (16.7) | 105,344 (16.9) | 127,126 (19.2) |
| 90-94 | 64,509 (11.5) | 74,609 (13.4) | 77,464 (13.7) | 83,923 (14.3) | 93,356 (15.0) | 105,169 (15.8) |
| 95-99 | 27,535 (4.9) | 28,988 (5.2) | 38,494 (6.8) | 45,284 (7.7) | 55,692 (8.9) | 67,587 (10.2) |
| 100+ | 5,315 (0.9) | 6,423 (1.2) | 886 (1.6) | 13,579 (2.3) | 19,321 (3.1) | 28,565 (4.3) |

Source: ONS. Mortality statistics: Deaths registered in 2010. ONS. Projected number of deaths obtained upon request.

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Cancer and dementia especially relevant (p. 21)

- A substantial number of people will be dying from cancer and dementia (main or contributory cause of death)
 - Annual numbers of UK cancer deaths expected to increase 30% for men and 12% for women by 2023 (Olsen et al *Br J Cancer* 2008)
 - Projections show over 1 mi people with dementia in the UK in 2021; by 2050 one in three people to die with dementia (Alzheimer's Society 2013)
- Increased disability likely to increase demand for beds in care homes and similar settings



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Key messages from Section 3 (p.21)

- **Change in pattern of mortality: people living longer and dying of chronic conditions at an older age**
- **Increase in numbers and proportions of home deaths**
- **But only marginal increase in numbers and proportions of inpatient hospice deaths**
 - Also non-cancer patients, women and the oldest old still die less often in these settings
- **Decrease in number of institutional deaths, with decrease for hospitals and increase for care homes**
 - 1/4 women's deaths, more than 1/3 of 85+ deaths in care homes
- **UK population to increase, accompanied by an increase in deaths for older people – very soon**
 - Number of deaths due to cancer, dementia and other chronic conditions will increase – need for hospice care will increase
- **Limited data on hospice care capacity/usage**

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References

- Help the Hospices. Hospice and Palliative Care Directory. United Kingdom and Ireland 2012-2013. Help the Hospices, 2012.
- Griffiths C and Brock A. Twentieth Century Mortality Trends in England and Wales. Office for National Statistics, 2003.
- Office for National Statistics. 2010-based Period and Cohort Life Expectancy tables. Office for National Statistics, 2011.
- Cancer Research UK: <http://www.cancerresearchuk.org/cancer-info/cancerstats/incidence/age/#Cancer> Accessed 10 Jan 2013
- Stephan B and Brayne C. Prevalence and projections of dementia. In: Downs M and Bowers B, (eds.). Excellence in Dementia Care: Research into Practice. Maidenhead: Open University Press, 2008, p. 9-34.
- Gomes B, Calanzani N and Higginson IJ. Reversal of the British trends in place of death: time series analysis 2004-2010. *Palliat Med.* 2012; 26: 102-7.
- Olsen AH, Parkin DM and Sasieni P. Cancer mortality in the United Kingdom: projections to the year 2025. *Br J Cancer.* 2008; 99: 1549-54.
- Alzheimer's Society. Statistics. Alzheimer's Society, 2012.

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Section 4. Where people wish to be cared for and die: meeting preferences (p. 22)

International evidence

- Preference for home ranged 49% to 100%, followed by hospice (Higginson and Sen-Gupta *J Palliat Med* 2000)
- Variation across populations (patients, public, caregivers), care settings, illnesses, methods of eliciting preferences
- Non-cancer patients choose home less often than cancer patients (Murtagh et al *NIHR SDO programme* 2012)

UK evidence

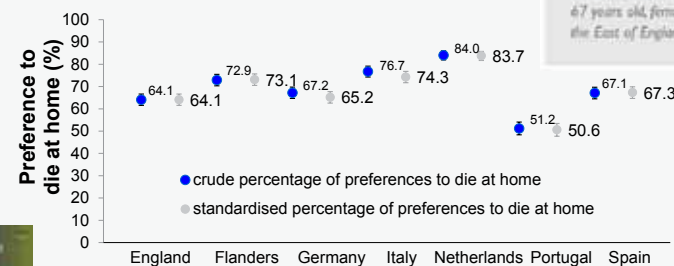
- 27 studies (15 internal audits in specific care settings)
- Home most common preference (32% to 85%)
- Inpatient hospice second place (2% to 38%)

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PRISMA survey in 2010 (n=9344)

Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain



Gomes et al *Ann Oncol* 2012

"In an ideal world we would like to die in our bed surrounded by our family. To achieve this we need specific care"
67 years old, female resident in the East of England

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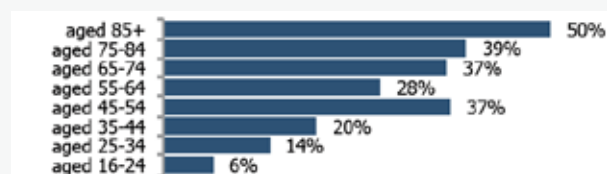
What shapes a preference for dying in hospice/palliative care unit in England? (n=1351)

- 29% would prefer to die in a hospice/palliative care unit
- No significant differences by geographical region

Two factors independently associated with hospice preference

- Having more important priorities than dying in preferred place
- Age

Percentage of PRISMA survey participants with a preference for dying in a hospice/palliative care unit by age group



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How frequently are people's preferences for place of care/death met?

International evidence

- 18 studies, congruence 30% to 90% (Bell et al *Palliat Med* 2009)
- Preferences more frequently met for those who die at home
- Expressing preferences influences dying in place of choice

UK evidence

- 8 studies, congruence 38% to 93%
- Preferences more often met for those who die at home (Karslen & Addington Hall *Soc Sci Med* 1998; Grande et al *Palliat Med* 2009)
- Promising initiatives:



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Key messages from Section 4

- International and UK evidence that home and hospice are the most preferred places for dying
- PRISMA survey findings show that:
 - Older people are more likely to prefer to die in a hospice/palliative care unit than their younger counterparts
 - Assessing priorities for care is as important as assessing preferences
- Preferences more often met when people die at home
- UK initiatives suggest that collaboration is key to allow people to die where they wish, but further evaluation is needed

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Section 5. Evidence that hospice care makes a difference to patients and caregivers (p. 28)

Impact on patients

Evidence of benefits regardless of setting

- Meta-analysis of palliative care teams show improvements in symptom control, especially pain (Higginson et al *JPSM* 2003)
- Meta-analysis of Hospital at Home and RCTs of palliative care show greater satisfaction with care, increased chances of home death or of dying in the preferred place (Shepperd et al *Cochrane* 2012)
- **However...**insufficient or conflicting evidence on psychological symptoms, functional status and quality of life (Salisbury et al *Palliat Med* 1999; Zimmerman et al *JAMA* 2008; El-Jawari et al *J Support Oncol* 2011)

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Impact on family caregivers

Much less evidence than for impact on patients

- Recent reviews report improvements in family caregivers' anxiety and satisfaction with care (Higginson and Evans *Cancer J* 2010; Candy et al *Int J Nurs Stud* 2011; Harding et al *Palliat Med* 2012)
- **However...** limited evidence on other psychological well-being measures, and very scarce evidence on bereavement outcomes (Grande et al *J Palliat Care* 2004)
- Range of models evaluated remains narrow and robust studies with validated measures needed (Harding et al *Palliat Med* 2012)

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The cost-effectiveness of hospice care

- Not enough evidence to confirm that hospice care is more cost-effective than standard care
 - Systematic reviews with mixed results on costs (Hearn et al *Palliat Med* 1998; Zimmerman et al *JAMA* 2008); more consistent on resource use reduction, particularly hospital days (Hughes et al *Health Serv Res* 1997; Higginson and Evans *Cancer J* 2010)
- Two RCTs: cost savings AND better outcomes
 - **52 MS patients (UK):** savings of £1,789 per patient for 3 months in mean service costs, incl. inpatient care and informal care (Higginson et al *JPSM* 2009)
 - **298 COPD, heart failure, cancer patients (US):** Costs for those receiving in-home palliative care (available 24/7) 33% lower than for those receiving usual care (Brumley et al *JAGS* 2007)



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More critical gaps in evidence

- We do not know which models of hospice care work better
 - Positive results: when there is close collaboration between different services, and service models are strongly based on evidence and piloted
- Inpatient care seen as the “gold standard” by those who receive it (Department of Health 2012)
 - What aspects makes it so good and can these be transferable to other settings?
- Is dying at home better for patients and families?
 - Contradictory findings, particularly on pain and grief (Parkes *J R Coll Gen Pract* 1978; Pinzon et al *Am J Hosp Palliat Med* 2011; Addington Hall and Karlson *Palliat Med* 2000; Wright et al *JCO* 2010)



QUALYCARE study

For better care at the end of life

(protocol in Gomes et al *BMC Cancer*, 10:400)

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Key messages from Section 5

What we know

- Hospice care is beneficial for patients regardless of setting (particularly on pain, symptom control and satisfaction with care)

What we still need to know

- Impact on caregivers (special attention to bereavement outcomes)
- Cost-effectiveness
- Which hospice care models work better?
- What makes inpatient care so good?
- Is dying at home is better?

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Report limitations

Related to the data

- place of death coding in mortality and preferences analyses
- survey response and hypothetical scenario
- projections modelled on assumptions (not deterministic)
- nationwide findings (need to consider local variations)

Related to scope of the report

- excludes children
- excludes other factors might also influence hospice care needs (e.g. social inequity, social care)
- focus on overall mortality, cancer and dementia
- studies and data beyond search strategy

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Summary of key findings

- Increasing demand for hospice care
 - Numbers of deaths to begin to rise in just two years time
 - Ageing, deaths by chronic diseases and complexity already increasing
- Home and hospice: people's preferred places for dying
- Older people continue to die less often at home and in hospice
- Evidence that hospice care makes a difference for patients and families but crucial gaps remain
 - Impact on bereavement outcomes
 - Cost-effectiveness
 - Comparative effectiveness
- Fruitful UK initiatives in both practice and research

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Acknowledgements

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2. A hospice response: questions and opportunities. Dame Barbara Monroe

A HOSPICE RESPONSE: QUESTIONS RAISED AND OPPORTUNITIES IDENTIFIED

Dame Barbara Monroe
CEO St Christopher's Hospice London UK
Honorary Professor International Observatory
on End of Life Care Lancaster University



EVIDENCE – ARE WE STILL JUST A “GOOD THING?”

- What have we been doing about data? Reliability?
- What is a “home death”?
- Gaps: Service utilisation and configuration, 24x7, hospital admissions, caregivers, bereavement, what informs “quality”?
- Supporting older people
- Outcomes: what support is most effective for whom, at what cost?
- Confused by marketing efforts
- How to share good practice and mistakes to inform the future? Better research partnerships
- How to ensure product is wanted? Different user engagement



WHAT WE THINK WE KNOW WILL CHANGE

- Unmet need will rise
- New populations with new needs and new preferences will require new services
- More deaths in late old age, fewer carers and more fractured, more cancer, more dementia, multiple illnesses
- Crude understanding of preferences and “trade offs”; too much emphasis on “place”
- Advance care planning as the “norm” – ongoing and anticipatory



IS THE CULTURE AND WORKFORCE FIT FOR PURPOSE?

- Training to drive change – huge opportunities
- A third of GPs have never had an ACP conversation (NCPC 2012) “CPR is the default setting in hospitals” (Time to intervene 2012)
- Producer interests and the inertia of “the way we do things”
- Do professionals work where they need to?
- Who supports care homes?
- Co-location, across settings, task not role
- 24/7



OPPORTUNITIES TO SUPPORT THE DRIVE TO THE COMMUNITY

- Co-ordination centres – utilising expertise and leading integrated and reliable health and social care
- Social care offerings
- Out patient and day services – hospice as “hub”
- Different levels and unbundled packages of care; involved longer and sporadically; managing professional assumptions, rehabilitation and survivorship
- Supporting transitions and achieving fewer of them
- Partnerships with care homes
- Locally driven responses



A CHALLENGE TO THE DRIVE TO THE COMMUNITY

- Hospital isn't going to disappear
- More demand for hospice beds
- Half way houses?
- How to "think smarter" about supporting beds elsewhere
- Understanding preferences – public knowledge of "hospice supported care"?
- "Dying at home doesn't necessarily mean dying well"
- Inequities - support for frailty?



FRAILITY (JANE SEYMOUR AND CECO)

- Frailty shapes needs in last year of life – not just final illness – holistic
- Discriminatory practices can lead to fragmented decisions and poor quality care
- Danger of over-emphasising physical and functional – mental health and dementia
- Social factors are vital
- Regular, planned, co-ordinated assessments
- Support for carers
- Using volunteers for peer education and community engagement (Seymour 2011)
- "Preventive and proactive"



RESOURCING CHANGE: VOLUNTEERS WILL BE KEY

- Are there limits to community development?
- "What would it take to.....?"
- Older people as active, younger people as entry to paid employment
- Change the "paid staff" restrictions
- Reciprocity. Training improves diversity. St Christopher's 37% under 48, 40% male, 28% BME
- Accreditation and apprenticeships
- Volunteer mentoring and management support roles
- Research, information signposts etc. but... housework
- Volunteers as the continuity?



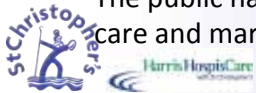
WHO ARE “OLDER PEOPLE”?

- New ways to engage with them as customers, carers and funders
- Are we out of step? Assisted dying and LCP furore. Shift in America re: “death”...
- They are the “driver of costs” – but what about social equity and deprivation? U.S. evidence of “cherry picking” (Wachterman et al 2011)



FUTURE ECONOMIC MODELS/INCOME GENERATION?

- Imperative to develop models of care less demanding of resources
- Complexities of PCFR and potential ‘top up’
- Dilnot, social care and insurance
- Other entrants – BUPA – new alliances?
- Personal budgets – paying for care – expectations of donors
- Learning internationally and from other sectors
- The integration of commission workstreams
- The public narrative – telling a clear story about complex care and marketing it effectively to all stakeholders



NEED SCALE TO MEET THE CHALLENGES

- “A queue is a sign of failure”
- Collaboration or competition – challenges of trust in the current environment
- Is a common platform a possibility – ourselves and others?
- We have to make it so
- New partnerships and collaborations
- Need to develop strategic, politically adept leadership and management based on rigorous analysis and planning. Remember middle management

Specialist/generalist? An effective response to need requires a broader offer



CREATING SERVICES FIT FOR THE FUTURE - HOSPICES BRING:

- Rooted in individual patients and families, friends and communities (risk in giving all inpatient care to acute hospital system)
- Understanding that care is a partnership not a commodity
- Already deliver health and social care
- Repositories of professional, compassionate confidence and competence
- A superb resource for training and education, delivered by those who do it
- Multi professional teams accustomed to working together who can support complexity
- Idea to action time is short – (share and learn from our mistakes)
- People need to belong – short distance from top to bottom of organisation

BUT need to get business-like – find the right models for funding and service delivery (Temel et al. 2010)



3. Looking forward: implications for practise and research. Professor Irene J Higginson



**Current and future needs for hospice care:
An evidence-based report**

**Looking forward:
Implications for practice and research**

Professor Irene J Higginson
Professor of Palliative Care and Policy
Head of Department and Director of Cicely Saunders Institute
King's College London

Brief summary

- **Public, patients and families preferences for hospice care** – UK studies show that a preference for dying at home prevails, followed by hospice, but place of death varies
- **Crucial factors for hospice care planning, including most recent actual and projected mortality data** – rapid ageing, more deaths 2015 onwards, home deaths on the rise, but hospice inpatient deaths remain the same
- **Effectiveness and cost-effectiveness of hospice care** – effective for patients regardless of setting, inpatient care seen as “gold standard”, but less evidence comparing models, family outcomes and cost-effectiveness



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Looking forward

Evidence from the report to trigger debate about future requirements and opportunities for hospice care and how these are best met in the future

- Helping individual hospices to develop strategically
- Helping to set the agenda for the Commission

No doubts about a challenging future

How will we make better use of hospice beds to accommodate more people according to preference?

How will we accompany the growing number of older people dying with chronic conditions?

Hospice care to grow with solid grounds
Practice, evidence and research working together

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What the evidence from the report means in terms of action

1. Implications for practice
2. Implications for research

To get the best for patients and families practice to be based on good evidence



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Implications for practice: Key recommendations to sustain growth



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1) Increase the availability of hospice beds and/or investigate optimal ways to use the number of existing inpatient beds

- Gap between preferences for dying in hospice (second to home, mostly by around 1/4 in UK studies) and hospice deaths (5.4% in England and Wales, 2011)
- Gap between preferences and reality for dying in hospice largest for **older people** - group that will grow in the future
- Number of deaths predicted to increase from 2015 onwards – will increase the need for hospice care overall, including for beds



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2) Diversify and evaluate the existing care models, collaborating with other providers and specialities (e.g. disease-specific, geriatrics)

- Home still dominant preferred setting, hospitals where most people die, care homes increasingly relevant
- Care models to adjust to complex socio-demographics (e.g. older patients and carers, dementia, less family support)
- Promising UK collaborative models (e.g. palliative care service for MS patients found to be cost-effective; Higginson et al JPSM 2009)

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3) Local strategic planning to meet needs and preferences, based on or generating evidence

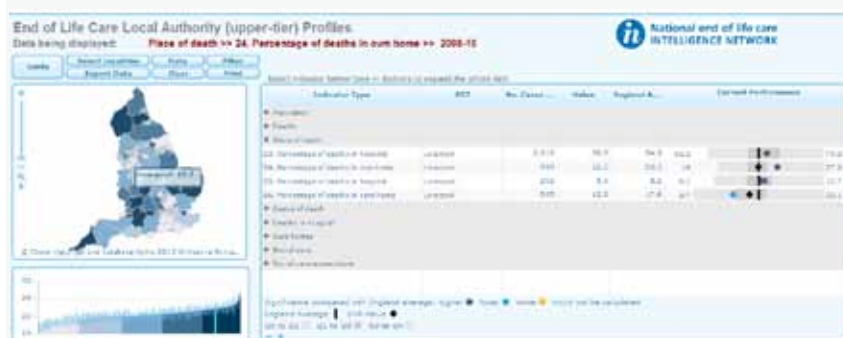
- Check data on your local population to accurately address hospice care needs
- Data sources on population-based drivers of need in the report (e.g. National End of Life Care Intelligence Network, ONS)
- Register and monitor your own data – more robust information about hospice usage and provision is needed!



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Data available for all local authorities from UK End of Life Care Intelligence Network, via South West Public Health Observatory, Verne J et al



www.endoflifecare-intelligence.org.uk

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4) Monitor outcomes to show complexity of care and achievements in hospice

- Validated, standardised measures are crucial
- Generic and specific measures can be used for different conditions
- Routinely** assess outcomes to evaluate the effectiveness of care provided
- Guidance on outcome measurement in palliative care available online:

<http://www.csi.kcl.ac.uk>



Outcome Measurement in Palliative Care
The Evidence

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**Implications for research:
need to generate evidence to support
future practice
critical questions still to be answered**



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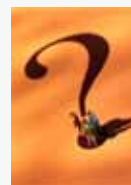
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1) Why do older people and non-cancer patients die less often at home and in hospices?

➡ **home death:** 14.1% of the 85+ and 18.9% of non-cancer deaths in 2011

➡ **hospice death:** 1.8% of the 85+ and 0.6% of non-cancer deaths in 2011 (little over 2100 people)

- Is the discrepancy due to inequities in access (e.g. referrals to hospice care)?
- Is it due to preferences?
- Is it due to ageism?
- Greater need of specialised care provided elsewhere (e.g. social care, mental health services)?
- Are new care models needed for these groups?



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2) How best to support family caregivers?

- Much less evidence of hospice care impact for caregivers than for patients
- Urgent need to evaluate bereavement care and identify which models are most effective
- Caregiver support interventions needed in all settings: home, hospital, hospice, care home



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3) Unsolved questions on the effectiveness and cost-effectiveness of hospice care

Evidence to 'fight our corner' in wider health system

- Is hospice care cost-effective compared to standard care?
- What is the impact of hospice care on family caregivers?

Evidence to help hospices be even better

- Which care models are more effective and cost-effective, and what is it that makes them better than others?
- What makes the inpatient care provided by hospices be seen as the "gold standard" by patients and families, and are these aspects transferable to other settings?

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Take home messages (1)



- Escalating number of older people dying with chronic, debilitating conditions will require greater availability of hospice and palliative care in varied settings – investment is needed
- Supporting people at home is the priority but increasing hospice / specialist palliative care beds are also needed as preferences for this setting are second and are expected to increase
- Ways to better use existing hospice / specialist palliative care beds should be investigated – this requires more robust information on hospice capacity and usage

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Take home messages (2)



- We know hospice care can be more effective than standard care and that inpatient hospice is seen by patients and families as the “gold standard”
- A lot still to be known in terms of impact on family caregivers, cost-effectiveness and comparative effectiveness – partnership with academic research centres can aid the design of robust evaluations
- **Urgency** for recommendations to come into practice – numbers of deaths to increase from 2015 onwards but ageing and chronic disease trends already started

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Acknowledgements



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4. End of life care for frail older people in care homes. Dr Jo Hockley



Thinking differently ... Development of end of life care for frail older people in care homes: a case study

Jo Hockley RN PhD MSc SCM
Nurse Consultant
Care Home Project & Research Team
St Christopher's Hospice

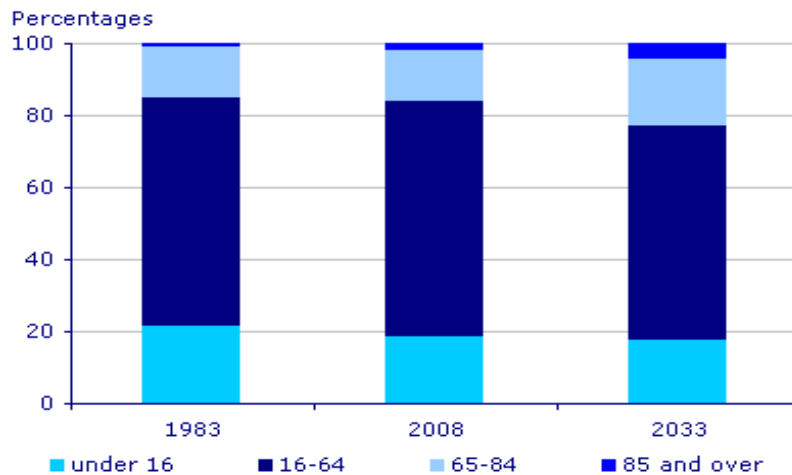


Overview

- ☐ Why do we need to think differently about frail older people in care homes?
 - ☐ Demographics & context of CHs where older people die
- ☐ Work of the Care Home Project & Research Team
 - ☐ Different ways of practice development
 - ☐ Different ways of teaching
 - ☐ Different ways of doing research

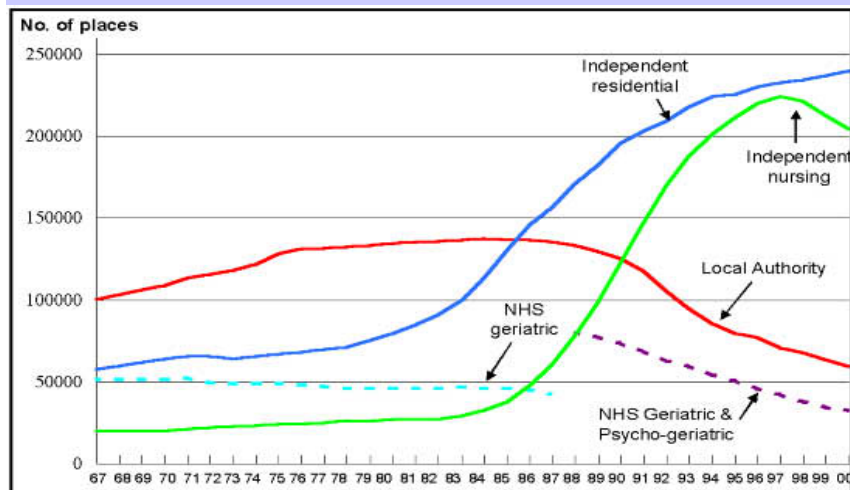


Population: by age, United Kingdom



Nursing and residential care places for elderly, chronically ill and physically disabled by sector, UK, April 1967-2000

(Laing & Buisson, 2002)



Care Homes

- In England there are **over 18,000** care homes for frail older people
 - 4,300 – nursing care homes
 - 14,000 – residential care homes
- 3 times as many care home beds than NHS (Badger et al 2009)
- Place of death (NEoLCIN, 2012):
 - 18% population die in care homes
 - 5% population die in hospices



Differences between hospice/SPC units & NCHs

(Hockley 2002; 2006)

Specialist Palliative Care

- Multi-disciplinary model of care with critical review of practice
- Focus on one disease and rare to have cognitive impairment
- Person-centred care
- Both patient & family often want life extended
- See life being 'cut short'

End-of-life care in NCHs

- Nurses & care workers (with little/no PC training)
- Multiple co-morbidities – 80% residents degree of dementia
- Tendency to task orientated
- Greater concept of becoming a burden
- Natural ending clearer but more complex trajectory



Differences between hospice/SPC units & NCHs

(Hockley 2002; 2006) *continued*

Specialist Palliative Care

- Good support from family
- Staff valued – little recruitment/retention issues
- Palliative care often over a number of months
- To live until you die (dying already diagnosed)
- Charitable

End-of-life care in NCHs

- Care staff seen as family
- Staff undervalued – no sick pay, no pension
- Longer dependency – staff can know residents for year/s
- Living/dying context (death often not diagnosed)
- Residents pay 'top up' fees





'Weak context' of nursing care homes (Hockley 2006)

Relative '**weak**' **context** of nursing care homes:

- High turnover of staff
- Lack of a learning culture
- Mostly untrained staff
- Lack of m/disciplinary input
- Lack of traditional audit & research culture



Weak context requires 'high facilitation' (Kitson et al 1998)

What is high facilitation?

- Use of evidence-based tools
- Experienced change agent
- intense input + sustainability initiative
- Supporting and empowering staff within the 'weak' context
- Education is not enough to change practice
(Froggatt 2001)



St Christopher's Hospice – regional training centre for GSFCH

- Population of 1.4million across 5 PCTs
(Bromley, Croydon, Lewisham, Lambeth & Southwark)
 - Just under 150 care homes
 - 71 NCHs
 - Team consists of:
 - Nurse consultant
 - 4.2 FTEs specialist nurse practice developers
 - 2.6 FTEs project researchers



End of life care tools to help guide high quality care

■ Structures for last year of life

- Gold Standards Framework for NHs



- Route to Success (DH 2010)
 - Steps to Success (our RHs)



■ Structures for last days/week of life

- Integrated Care Plan for the Last Days of Life for Care Homes



High facilitation... doing practice development differently

- ❑ Visit/contact with care home 2-3 times a month for the duration of the programme implementation
- ❑ Role modelling of:
 - ❑ Advance care planning discussions
 - ❑ Monthly review meetings about all residents (with GP)
 - ❑ DNaCPR orders will be discussed
 - ❑ Symptom control issues:
 - ❑ PAIN, DEPRESSION, CONSTIPATION
 - ❑ Reflective de-briefing groups following a death
- ❑ Help to build relationships with GPs and DNs – and social services/monitoring team

Comparison of data on DNaCPR; ACP & ICP – 2009 to 2012

Care Home Project Team, St Christopher's, London

| | PCT 1 | PCT 2 & 3 | PCT 4 | PCT 5 | Total |
|---------------------------|-------------|-------------|--------------|-------------|-------|
| DNaCPR: | | | | | |
| 2009/10 | 43% (n=155) | 41% (n=265) | 68% (n= 384) | 54% (n=271) | 52% |
| 2010/11 | 45% (n=218) | 74% (n=329) | 75% (n= 435) | 71% (n=397) | 66% |
| 2011/12 | 75% (n=214) | 84% (n=284) | 86% (n= 492) | 76% (n=361) | 80% |
| ACP: | | | | | |
| 2009/10 | 48% (n=155) | 44% (n=265) | 60% (n= 384) | 51% (n=271) | 51% |
| 2010/11 | 62% (n=218) | 61% (n=329) | 74% (n= 435) | 63% (n=397) | 65% |
| 2011/12 | 76% (n=214) | 60% (n=284) | 83% (n=492) | 79% (n=361) | 75% |
| ICP for last days: | | | | | |
| 2009/10 | 33% (n=155) | 5.5%(n=265) | 44% (n=384) | 17% (n=271) | 25% |
| 2010/11 | 59% (n=218) | 30% (n=329) | 60% (n= 435) | 37% (n=397) | 47% |
| 2011/12 | 70% (n=214) | 51% (n=284) | 72% (n= 492) | 59% (n=361) | 63% |

Comparison of place of death across nursing homes

Care Home Project Team, St Christopher's Hospice [2007 to 2012]

| 2007/2008 | 2008/2009 | 2009/2010 | 2010/2011 | 2011/2012 |
|--|----------------------------------|-----------------------------------|-----------------------------------|-----------------------------------|
| Percentage of deaths occurring in NHs [numbers of deaths] | | | | |
| 57% | 67% | 72% | 76% | 78% |
| n=324 deaths across 19 NHs | n=989 deaths across 52 NHs | n=1071 deaths across 53 NHs | n=1375 deaths across 71 NHs | n=1351 deaths across 71 NHs |



Demographic to be collected on ALL CHPT's nursing/residential care home residents who died from Sept 2012 – August 2013

| Nursing Care Home Code: | | | | | | | | | | | | |
|-------------------------------|--------|-----|-----|-----|-------------------|--------------------------------|---|--|---|--|--|--|
| Resident Initials | Gender | Age | DOB | DOD | Current diagnosis | Doc. evidence of DNaCPR Yes/No | Doc. evidence of ACP or 'best interests' meeting Yes/No | Use of BCP or Minimum Protocol (if YES state BCP or MPP) | Number of hospital admissions in last month of life | Place of death: NH, hospice or hospital. NO if recently discharged from hospital state no. of days prior to death | If hospital death please complete TIME of admission = who requested admission | Short summary re death = type of death: D, S, A, T |
| | | | | | | | | | | | | |
| | | | | | | | | | | | | |
| | | | | | | | | | | | | |
| | | | | | | | | | | | | |
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CHPT – Practice Development

Practice:

- ❑ GSFCH – in 71 NCHs [61% accredited]
- ❑ Steps to Success – in 22 RCHs

Audit:

- ❑ Monthly NCH audits
- ❑ Family Perception of Care (9 NHs - Croydon)

Projects:

- ❑ Implementing 'stock' end of life care medication into GSFCH NCHs
- ❑ Coordinate My Care/nursing homes



Doing education differently... the role of 'reflection' following a death

The need for support:

"Death isn't something you've face before you come and work here...I never thought I would be dealing with dying when coming to work in a nursing home....to think a death has happened in a building that you've been in is terrible" [CA, FG4]

Its not as though I haven't worked anywhere else. I worked fro 17 years in the hospital on night duty, so it is not as though I've not come across this [death/dying]. I think it is in here – it is more personal – somehow here it is closer [CA, NH1, FG1]



Reflective de-briefing Groups (Hockley 2006)

- What happened?
 - *Describe own & other's actions*
 - *Different times, shifts, experiences*
- How did the participants feel?
 - *Explore personal + interpersonal feelings*
 - *Anticipate unexpected expressions of emotion*
 - *What was 'good' ...what was 'bad'*
- What does it mean?
 - *Come to some conclusion of various events...what has been learnt / what needs changing*



NAMASTE CARE project



AIM:

- to establish whether NAMASTE CARE improves the quality of end of life care for residents with very advanced dementia and their families, and improves staff job satisfaction

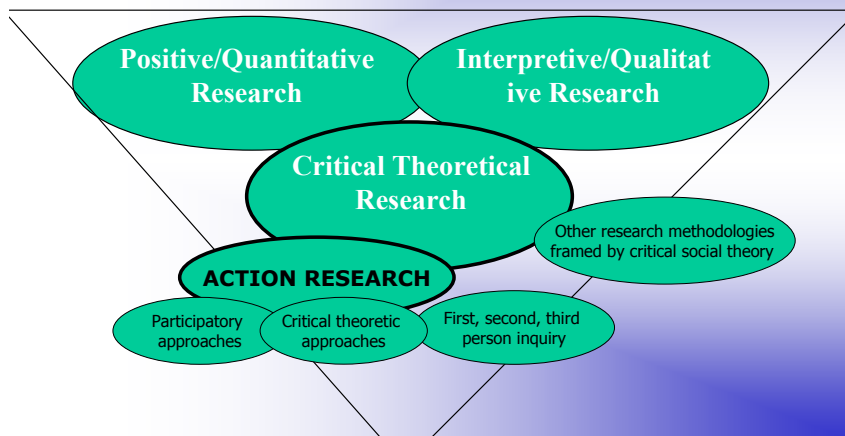
Design:

- an action research evaluation study in 6 NCHs/specialist care units



Action research and its position within the research paradigms:

(adapted from: McNiff & Whitehead 2002)



NAMASTE CARE - KEY ELEMENTS

Creating a Namaste space in order to achieve a good quality of life for a person with advanced dementia with the ultimate goal of a dignified death:

- The presence of others – rather than isolation
- Sensory stimulation of 5 senses: sight, touch, taste, hearing, smell
- Meaningful activity associated with the biography of the person
- Staff education
- Family conference to alert change to end-stage
- Care of the dying and family after death





Celebrating Care Homes 2013
Two day Conference - optional 1 or 2-day attendance

Day 1
9 May 2013, 10.00-18.00
Bloomsbury Holiday Inn, London
Early Bird booking offer for Day 1
£120 if booked by 10 November 2012, £150 thereafter

Day 2
10 May 2013, 9.30-16.00
Education Centre, St Christopher's Hospice £50
Code CH0513



Chair
Dr Jo Hockley
St Christopher's Hospice

Keynote Speakers
Prof Joyce Simard
Founder of NAMASTE,
Florida, USA

Prof Kevin Brazil
Hon Professor,
Division of Palliative Care,
McMaster University,
Canada

Thank you

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